

Stories Snapshot

Stories from women with disabilities on accessing sexual

& reproductive healthcare



Welcome to AcceSex Stories Snapshot

Women with disabilities voices often aren't heard when it comes to talking about sex.

Abled bodied people tend to silence or dismiss our concerns.

Able bodied people's opinions and stereotypes about our lives and bodies are listened to more than our actual voices.

Women with disabilities have a right to fun and enjoyable sex with partners who respect them every day.

This is an opportunity to hear our stories about accessing sexual and reproductive healthcare.

We invite you to read these personal accounts with an open heart and mind.

We want you to be challenged and to think differently about how you view women with disabilities and our sexual and reproductive health.

If you want to learn more about women with disabilities' experiences, we recommend checking out our website.



The first time Susan's story

"The first time I visited a gynaecologist to be prescribed the pill, I really felt like I was a dummy. Visiting the gynaecologist is never a pleasant experience, especially as a young person.

When the doctor instructed me to go into an area separated by a curtain to get undressed, her voice became muffled. Being hearing impaired, I couldn't understand her properly anymore,

which led to some misunderstandings.

When I got up on the table, I realised she had started talking slowly to me, as if I needed time to process information. She also became quite patronising, explaining to me that sex could be scary, but I shouldn't be afraid.

The whole appointment was quite unsettling, and I didn't return to a gynaecologist for another 8 years."

Susan*

TIP: Clear communication does not mean talking down or speaking like you would to a child. If the information is complex or there are

 Stop and ask questions to check understanding

misunderstandings it is best

to:

- Use plain language and avoid acronyms to explain topics
- Clarify any access requirements at the start of the appointment

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"That tone was definitely NOT welcome."

- Lisa's

story

"A few years ago, my doctor sent me for an ultrasound on my uterus, involving an internal probe. When making the appointment, I specified that it should be done by a female radiologist, and was assured that it would be.

Imagine my shock when, on reporting in, the receptionist informed me that a bloke would be assigned to me for the exercise. So shocked that I commented, only to be told that you are assigned to radiographers randomly. So shocked that I stayed. I asked for a rescheduling to ensure a female radiographer, and was told that as it was random, there was still no quarantee. GRRRRRRR.

I went into the radiology room (after changing into the gown) with the bloke, and he was surprised when I told him that there was NO WAY that he would be using the internal probe.

What followed next was the odd bit. When he was looking at the screen, which I could also see, he commented, "That's interesting" in a very voyeuristic tone.

Yes, my uterus is quite oddly shaped, one of my birth defects. Being told so by a bloke in that tone was definitely NOT welcome. So pleased that I went with my first reaction and did not let him do the internal bit.

On reflection, I wondered about the "what ifs" – what if I was a younger woman/ teenager and didn't know that I could refuse the internal bit?"

Lisa*

FACT: Disability is a natural part of human diversity.

Women with disabilities have a right to make choice about healthcare including service providers who can meet their access needs.



"Finding the right option for birth control [contraception] was a tricky experience for me. I manage complex chronic health conditions and found that many birth control options led to unwanted side effects that made managing my health too difficult. I was particularly prone to severe nausea and bleeding from options including pill varieties and the Implanon.

I have received sexual and reproductive healthcare from a sexual health community doctor, and later was referred to a gynaecologist.

My experience was long, but I was happy with the treatment I received.

The doctors were friendly, welcoming, and inclusive of my conditions. What was good about this service was that they took a holistic approach and consulted with my other specialists and GP. The doctors were clear with communication, enabling me to make informed decisions. They valued my right to control my fertility and worked with me to overcome the

obstacles of my other health

Kate, 25

conditions."

TIP: Women with disabilities identify the best ways to make services inclusive and accessible are:

- A welcoming attitude toward women with disabilities
- Holistic and collaborative approach
- Clear communication
- Emphasis on informed decision making and consent

"Friendly, welcoming and inclusive" - Kate's story



"Ask her." -Frida's story

"I am a blind woman who, on becoming pregnant with my first child, was referred to a highly respected professor of obstetrics.

At each visit, the professor would welcome us with "How's Roxanne today?" Roxanne was my guide dog. Then he would ask my husband, "And how's Mrs. F...?" I felt that I was just the baby carrier. Naturally, I answered all his questions.

On our subsequent visits, my husband would often say, "My wife is the one having the baby. Ask her."

At my final visit, my baby wasn't moving and had a faint heartbeat. Without consulting me first, the professor told the Registrar that I would be admitted immediately, induced the following morning, and have an epidural for the delivery.

The Registrar saw how distressed I was and promised me that he would explain everything and unless I agreed I need not have an epidural for delivery." - Frida*

TIP: Women with similar disabilities each have different experiences. For example, not all blind people are the same or have the same experiences.



Exploring safe and accessible sex-Tahlia's story

"I have a physical disability so when I wanted to have sex with my boyfriend for the first time, I wasn't sure who to go to about exploring safe and accessible sex positions for my body. I asked my physiotherapist about this and we explored some different positions together.

During our discussion we talked about the importance of consent, not being coerced and the main focus being about my pleasure.

Although the conversation was uncomfortable at times and we shared many laughs, my physio reassured me that sex is a basic human need and thanked me for coming to her for help, especially because when combining sex and disability together it is still taboo.

She told me that she thought her other clients would be too embarrassed to tell her about this. She didn't want this for me. She wanted me to fully experience life in a way that was inviting and enthusiastic."

TIP: Sex is fun and funny! Too often people get scared when we mention sex and want to protect us from 'consequences'. We do not need protection from able bodied people. We need information, choice and respect for our decisions.

Tahlia*



"This is my story of trying to access health care for menopause, as a woman with a brain injury, chronic pain and PTSD [Post Traumatic Stress Disorder]. I started experiencing difficult peri menopausal symptoms when I was 43. I thought I had a pretty good GP, but she outright dismissed my concerns, saying I was too young. Even after I found a study that indicated that women with ABI [Acquired Brain Injury] can get earlier menopause, but she still refused to listen.

My symptoms quickly increased to include intense panic and suicidal feelings, but my GP insisted that this was due to the stress from my university studies, and an exacerbation of my PTSD. I dropped out of my studies and many other life and health activities (including this GP) as I struggled to stay alive. I did try to find another GP. But it was 4 years before I found one willing to listen, although by this time, I was a year post menopause and the worst was over. It was a bittersweet moment.

I so wish that any of the GPs I saw, had listened, given me support and offered treatment. I believe it would have made the world of difference. Instead, today at 52, I feel as if I only just survived those peri menopausal years, and that I may carry the trauma of those years for some time yet."

Lesley*

"I so wish that any of the GPs I saw had listened" -Lesley's story



"Should you be having this baby?" - Janene's story

"Both my husband and I have Achondroplasia a form of Dwarfism, we knew when it came time to start a family there would be questions, we did not expect ignorance and judgement.

I was asked by a doctor during emergency department visit early in my pregnancy, "should you be having this baby?" again I played dumb and asked, "what do you mean?". Again, he said "should you be having this baby, you know with your condition?" meaning my Dwarfism.

He was not concerned about my wellbeing he was concerned about bringing a child into this world that could possibly have the same genetic condition as me.

I relieved him of his concern by letting him know the baby does not have the same genetic condition."

Janene*

TIP: The issue of discrimination and ableism is often not from individuals but from whole systems, such as the medical system. To ensure these complex systems are welcoming we must address wider issues by ensuring all staff from the triage desk, to the doctors must have a level of understanding and awareness of the rights of women with disabilities.



With thanks

The resource was produced by Women with Disabilities Victoria with funding from the Victorian Government Department of Health. This resource was created in Naarm (Melbourne) on the lands of the Wurundjeri peoples of the Kulin Nation. Always was, always will be Aboriginal land.

* Name changed

We would like to thank the women with disabilities from across Victoria who generously shared their experiences with us. Nothing about us, without us.

About Women with Disabilities Victoria

Women with Disabilities Victoria is an organisation run by women with disabilities, for women with disabilities. We aim to advance real social and economic inclusion for women with disabilities in Victoria.

For more information, see our <u>About</u>
<u>Women</u> <u>with Disabilities Victoria Factsheet</u>, or look at our website: <u>www.wdv.org.au/</u>

Membership is open to both individuals and to organisations who share our aims, and is free for women with disabilities.

https://www.wdv.org.au/getinvolved/membership/

